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# Maximal care considerations when treating patients with end-stage heart failure: ethical and procedural quandaries in management of the very sick

Ernst R. Schwarz · Kiran J. Philip · Sinan A. Simsir ·  
Lawrence Czer · Alfredo Trento · Stuart G. Finder ·  
Laurent A. Cleenewerck

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**Abstract** Deciding who should receive maximal technological treatment options and who should not represents an ethical, moral, psychological and medico-legal challenge for health care providers. Especially in patients with chronic heart failure, the ethical and medico-legal issues associated with providing maximal possible care or withholding the same are coming to the forefront. Procedures, such as cardiac transplantation, have strict criteria for adequate candidacy. These criteria for subsequent listing are based on clinical outcome data but also reflect the reality of organ shortage. Lack of compliance and non-adherence to lifestyle changes represent relative contraindications to heart transplant candidacy. Mechanical circulatory support therapy using ventricular assist devices is becoming a more prominent therapeutic option for patients with end-stage heart failure who are not candidates for transplantation, which also requires strict criteria to enable beneficial outcome for the patient. Physicians need to critically reflect that in many cases, the patient's best interest might not always mean pursuing maximal technological options available. This article reflects on the multitude of critical issues that health care providers have to face while caring for patients with end-stage heart failure.

**Keywords** Health ethics · Heart failure · Heart transplantation · Ventricular assist devices

The good physician treats the disease; the great physician treats the patient who has the disease - Sir William Osler

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E. R. Schwarz (✉)

Division of Cardiology, Cedars Sinai Heart Institute, Cedars Sinai Medical Center,  
8700 Beverly Boulevard, Suite 6215, Los Angeles, CA 90048, USA  
e-mail: [ernst.schwarz@cshs.org](mailto:ernst.schwarz@cshs.org)

K. J. Philip · S. A. Simsir · L. Czer · A. Trento · L. A. Cleenewerck

Divisions of Cardiology and Cardiothoracic Surgery, Cedars Sinai Heart Institute,  
Cedars Sinai Medical Center, Los Angeles, CA, USA

S. G. Finder

Center for Healthcare Ethics, Cedars Sinai Medical Center, Los Angeles, CA, USA

## The physician's task and dilemma

For physicians all over the world, daily practice is guided by and depends on biomedical sciences and modern technology, which can result in some degree of institutionalized and depersonalized health care. However, in spite of the variety of available technological options and guideline recommendations, physicians know by experience that in many instances, the best treatment options for a given patient are less than fully clear. Indeed, optimal care does not necessarily follow the rule of textbooks or recommendations issued by professional societies. Admitting an 'uncertainly principle' in determining the severity or progression of a condition should lead us to explore the implications of this limitation with regard to treatment decisions. On the opposite side of the spectrum, physician's self-reflection is especially sensitive when an unpredictable chain of events occurs and results in a catastrophic outcome for the patient despite adequate care.

It is our task as health care providers to provide objective criteria, including the potential risks and alternatives, so that patients may be in a position to make informed decisions. In practice, however, patients often lack the knowledge and capacity to make such decisions completely on their own. The consensus is that it is reflective of good medical care to be willing to assist patients in this way.

The physician must deal with a unique person and make recommendations that are suited to the patient's distinctive characteristics, based on his or her best knowledge and experience. Especially in the management of patients with ongoing symptoms of heart failure in spite of maximal medical therapy, it is now recommended to refer patients to centers with experience in the treatment of advanced stages of heart failure, according to the recently updated AHA/ACC guidelines (Hunt et al. 2009).

## Reasons for not providing maximal care in advanced heart failure

There are several reasons why health care providers may opt not to recommend or provide maximal care in certain cases. Among a few others, the main reasons health care providers are challenged within their decision-making process might be categorized as one of two physician-dependent criteria: therapeutic inertia and lack of resources, or one of two patient-dependent criteria: lack of compliance and lack of required psycho-social support.

### Therapeutic inertia

Therapeutic inertia can be defined as "the provider's failure to increase therapy when the treatment goals are unmet" (Okonofua et al. 2006). This has been primarily described in the treatment and control of blood pressure where health care providers do not always adopt an aggressive approach to reach the recommended goals (Fine and Jeffrey 2006). This is typically reflective of situations in which health care providers are unacquainted with or do not have access to more advanced therapies, but fail to disclose this to patients. In the context of patients with heart failure, this is often seen outside major medical centers where the capabilities to provide more advanced therapies such as left ventricular assist device (VAD) implantation or cardiac transplantation are absent. In particular, multi-organ transplantations or heart transplantations in patients of older age are rarely discussed with patients in less specialized centers, especially because many health care providers are unaware of more specialized therapies and limited acceptance of older recipients (i.e., above 65 years of age) for surgical options such as transplantation in ours as well as in

some other medical centers (Blanche et al. 2001). Since the incidence of heart failure is likely to increase over the coming years with subsequent requirements for physicians to care for patients with heart failure, more intensive educational activities for cardiologists, internists and general practitioners are recommended. In addition, the American Board of Internal Medicine (ABIM) in 2009 established a board sub-specialization for heart failure/transplant cardiology, and some institutions such as our own have developed fellowship programs for heart failure specialists cross-trained in cardiology as well as in electrophysiologic and minimally invasive surgical procedures.

### Resource limitations

There are many forms of resource limitations that are in part physician dependent, and in part contingent on the socio-cultural environment. In the context of cardiac transplantation, there is a dearth of well-trained transplant physicians and nurses. There is also a lack of information among health care providers about therapeutic possibilities, requirements for transplant listing, actual waiting periods and chances to receive an organ for transplantation, survival rates as well as options of multi-organ transplantation, especially combined heart-kidney transplantations (Blanche et al. 2001).

Greatest among the resource limitations, however, is the current lack of organs available for transplantation. As a result, the allocation of organs has been a major point of focus when considering the ethical dimensions associated with transplant medicine. As part of these considerations, strict criteria for adequate candidacy prior to listing for cardiac transplantation have been developed in order to ensure, even before the point of organ allocation, that only the most suitable candidates are selected (Mandeep et al. 2006). Such criteria include the existence of social support systems, compliance with medication and follow-up, as well as abstinence from alcohol, tobacco and other dangerous substances. Of course, the issue of limited donor supply is quite different from that of limited regional expertise or limited financial resources. Although both can be expressed in terms of resource limitation, they require different public and political health care approaches to overcome their consequences. Fostering a culture of altruism, with the support of society at large and of faith communities, has major implications on the development of positive attitude vis-à-vis organ donation (Schwarz and Rosanio 2009).

### Compliance

The requirement of patient compliance is crucial for therapies whose success greatly correlates with follow-through. As a result, psycho-social assessment has become an important part of the evaluation process of potential transplant candidates. Specifically, a patient's ability to give informed consent and to comply with instructions including drug therapy is of paramount importance. In addition, an assessment of support systems available at home or in the community must be made prior to a patient being accepted for heart transplantation. In this context, it is observed that conditions such as mental retardation or dementia are typically seen as contraindications, as is evidence of repeat non-compliance with drug regimen (Mandeep et al. 2006).

Continuous smoking or substance abuse indicates an overall lack of insight into the requirements of the condition. This typically indicates a bad prognosis, as has been documented after bypass surgery (Mehta et al. 2008). Poor social support, a family history of alcoholism and pre-transplantation abstinence of less or equal to 6 months have shown small but significant associations with relapse of substance abuse after (liver)

transplantation (Dew et al. 2008). It is also well established that smokers do worse than non-smokers after heart transplantation (Sánchez-Lázaro et al. 2007), also in terms of the development of renal dysfunction (Sánchez Lázaro et al. 2008) as well as malignancies and reduced graft survival (Botha et al. 2008). For this reason, our center as well as many others request a minimal period of 6 month abstinence from smoking, and some even require a contract including acceptance of random blood nicotine (cotinine) level tests.

#### Existence of adequate psycho-social support

This factor is crucial for long-term outcome after cardiac transplantation, because transplantation surgery requires support outside what health care providers can offer. The requirements for psychological, emotional and moral attention usually begin with facing a chronic and debilitating disease long before the day of the surgery but are amplified due to transplant-related specific matters. The main issues post-cardiac transplantation patients must cope with include (1) the initial recovery from surgery, (2) the need for life-long medication usage, (3) frequent repeated office visits, (4) the continuous risk of rejection of the transplanted organ, (5) the potential of viral, bacterial and fungal infections, (6) the long-term development of allograft vasculopathy, a transplant-related coronary artery disease, (7) the risk of development of malignancies, and (8) other co-morbidities that may impact quality of life. As a result, it is of utmost importance for all transplant candidates to have access to an effective support system, which will include one or more individuals who are able to accompany the transplant recipient for follow-up visits, provide transportation, ensure correct medication usage, provide emotional and social support as well as other elements deemed necessary for daily living.

Another important aspect related to outcomes is the financial burden many patients face when dealing with a chronic condition (such as organ transplantation) that requires continuous medical care and diagnostic assessment. Without financial means or assistance including adequate insurance coverage proportional to the high cost of immunosuppressant medications, the mid-term and long-term survival after transplantation is endangered.

Moreover, the involvement of a dedicated social worker is indispensable to provide psycho-social consultation throughout the evaluation and healing process. A financial coordinator would also ensure that the patients' insurance eligibility and benefits are adequate for transplant candidacy. If, however, this is not the case, the coordinator will explore such options as obtaining additional coverage or fundraising to cover the patient's future transplant expenses.

This evaluation process will support, not undermine, the patient's autonomy to make a decision for treatment based on his or her wishes and expectations. On the basis of these discussions and assessments, the long-term commitment and subsequent burden of post-transplant requirements might not be the best option for some patients, in which case alternative therapeutic options should be considered.

#### Mechanical circulatory assist systems

A therapeutic alternative to either medical therapy or transplantation for the treatment of end-stage heart failure is the use of mechanical circulatory assist systems, mainly left or bi-ventricular assist devices (VADs). Recently, the surgical insertion of VADs has emerged as an applicable possibility for a broader group of patients with advanced stages of heart failure, especially for those of older age and those with co-morbidities that exclude

transplantation (Esmore et al. 2008; Long et al. 2008). However, the use of VADs also requires patient-directed cooperative measures including: (1) the acceptance of having a mechanical device implanted in the body with an outside driveline requiring maintenance; (2) the intellectual ability to understand the system and to troubleshoot in case of a device malfunction; (3) strict adherence to hygienic and medical recommendations in order to avoid driveline infections that could be fatal; (4) adequate social support to provide all necessary means to help the patient at home and in the community after leaving the hospital.

The risks associated with ventricular device implantation can be significantly minimized with adequate patient cooperation. In particular, the incidence of device-related infections can be reduced by strict adherence to regular site cleaning procedures performed according to specific protocols (Zierer et al. 2007).

Altogether, considering a patient for a ventricular assist device—even though not part of any guideline recommendations, yet—also requires a thorough evaluation of the patients eligibility, compliance, psycho-social support among other conditions, similar but not identical to the evaluation process for transplant candidacy.

Unfortunately, in some cases, health care providers might not have enough time for a detailed assessment such as in cases of sudden cardiogenic shock. In such a situation, cardiologists and cardiac surgeons have to make decisions based on their initial evaluation and on the assessment of their peers. In this regard, the insertion of a VAD may sometimes be considered as a ‘bridge to compliance,’ i.e., as a means to save a person’s life in an emergent or urgent situation in order to ‘buy time’ to assess compliance for a potential transplant listing in the future. The ethical implications of such an approach are problematic, but this procedure is nevertheless adopted in many cases.

### **Not providing maximal care might in fact mean better care**

For a patient to make any decision about the best therapeutic option is rarely easy or ‘clear cut.’ Often, various treatment opinions exist among different health care providers or even between different health care teams within the same provider, which might lead patients and their families to seek second opinions among different institutions. In order to avoid misinterpretation of the reasons for treatment decisions and subsequent confusion, it is of utmost importance for the clinical care team to meet repeatedly with patients to discuss various options and recommendations. In our institution, we found that it may also be necessary to regularly re-evaluate the patients’ conditions, decisions and subsequently discuss possible next steps. In particular, if decisions are based on lack of social support, encouraging the involvement of individuals such as members of the patient’s family, close friends and organizations such as religious communities, support groups and other social communities might in some cases alter the situation and generate the necessary support. In order to pro-actively promote a sense of mutual responsibility in society, notably in situations that require exceptional aid, more educational initiatives should be encouraged. This effort should further be combined with the promulgation of altruistic and humane principles of societal co-existence which would be concerned with the unique needs of every individual member of society.

In general, health care providers should individualize every aspect of the treatment plan with consideration of all available options and in accordance with treatment goals discussed with the patients. In addition, the decision from a physician’s point of view whether or not a person with advanced heart failure is a candidate for more specialized therapies

such as transplantation or VAD insertion should not depend solely on an initial perception but rather on a thorough evaluation by a team experienced in the long-term care of such patients. Even if maximal therapy such as cardiac transplantation or the insertion of an VAD is a reasonable option, a patient with sound decision-making capacity might still decide otherwise.

### **Conservative and palliative care for end-stage heart failure patients**

Evidence-based medical drug therapy is the mainstay of treatment for symptom control as well as reduction of morbidity and mortality for all patients with heart failure. Medical therapy should always be offered as the first-line option but should not be presented to patients and their relatives as a last resort when more advanced surgical options are not suitable. This is even more important in view of the fact that more advanced technological options, such as heart transplantation or insertion of ventricular assist devices, can be used to (1) improve symptoms and (2) to prolong life.

According to the World Health Organization (WHO) definition from 2002, palliative care should be provided early in the course of the disease, in conjunction with other therapies that are intended to prolong life. Thus, palliative or supportive care should not be provided in a vacuum as an alternative to other treatment options but rather in the context of a comprehensive heart failure care model, as outlined in a recent review by Goodlin (2009). This is especially true in the case of such symptoms as anxiety, depression, chronic or intermittent pain syndromes, fatigue, dyspnea, sleep disorders, myopathy (possibly caused by cytokine activation and inflammation as a result of the systemic effects of ventricular dysfunction) which are usually not assessed in the diagnostic work-up of heart failure and not directly addressed using common treatment modalities. Palliative care can help not only with symptom-directed medical therapy such as adequate pain management but also support emotional and spiritual distress for patients and their caregivers (Bain et al. 2009). In our program, we involve members of the palliative care service (as well as spiritual care) at an early stage in the management of our patients.

### **Ethical considerations**

The considerations discussed in this article are bound to raise ethical questions. Is it ever ethically justifiable to withhold interventions that might potentially prolong life? As physicians, we are under the obligation to provide—not withhold—medical care. However, it seems that we must answer affirmatively to the question posed above: it is indeed justifiable—in certain cases—to withhold interventions that might potentially or theoretically prolong life? Specifically, it appears ethically justifiable to withhold maximal care if the result would be to adversely impact the patient's quality of life without curing the disease or significantly improving the overall condition. In patients with end-stage malignancies, it appears easier to opt for palliative or hospice care in view of the lack of curative treatments and because of the context of short life expectancy. For patients with advanced heart failure, the possible use of palliative and hospice care should be discussed, including the option of inactivating implanted defibrillators, which has been added to the recently updated ACC/AHA guidelines for heart failure (Hunt et al. 2009).

Withholding medical treatment without reason is quite different from withdrawing treatment in very specific end of life situations. However, this distinction and the proper

means to establish it in practice remains one of the most difficult medico-legal as well as ethical issues in modern medicine (Ulsenheimer 2008).

Interestingly, ethical issues are dealt with by patients, their families and healthcare providers quite differently depending on their geographic and religious background (Hynninen et al. 2008).

In all of these ethical issues, physicians find themselves in the peculiar situation of having the professional obligation to perform whatever is best for the patient, and this must be done in the context of shared decision-making. At the same time, health care providers must refrain from doing whatever might either conflict with the law or at least could raise legal concerns. As a result, it is incumbent that physicians be familiar not only with the standards of their professional organizations in terms of acceptable practices, but also with what the law does and does not prohibit. Especially when taking care of patients with heart failure, awareness of the various kinds of myths and biases that circulate around end-of-life decision-making is critical. In addition, these complex issues must be raised before the patients are in fact reaching their end-of-life state, since prolonged suffering due to aggressive invasive procedures with complicated recovery versus a life with symptom-oriented (palliative) therapy and a death with dignity should be discussed. Such discussion should certainly involve more than just the physician and patient since the implications are far reaching. Physicians must then be willing to interact with the patient's family and spiritual advisors to provide for an adequate decision-making process.

In general, any treatment decision should be based on a profound respect for the patient's autonomy balanced by an appreciation of what may be in the patient's best interest—the latter itself being deeply nuanced by a wide array of personal, professional, institutional, spiritual and societal values.

Continuous self-critical reflection of our daily clinical management decisions coupled with outcome analyses should be part of our routine practice of heart failure and guide our approach to best address the needs and expectations of patients faced with such extremely difficult decisions.

**Conflicts of interest statement** The authors have no conflicts of interest.

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